

The Caregiver

Newsletter of the Duke Family Support Program

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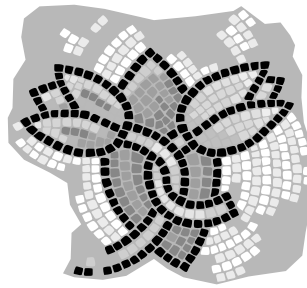
Spring 2005

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Duke University Center for the Study
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Alzheimer's Disease Research Center

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Subscriptions to this newsletter are available free to North Carolina residents. Call 800-672-4213 for details. See this newsletter online at www.dukefamilysupport.org.



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NORTH CAROLINA ALZHEIMER'S ASSOCIATION NEWS

Eastern NC Alzheimer's Association – The Alzheimer's Association is sponsoring Caregiver Education Conferences May 10, 13, 17; June 2, 15. The Annual Stand by Me Golf Tournament is on Monday, June 20th at the Preston Country Club in Cary. Please call the Chapter office at 919-832-3732 or 800-228-8738 or check www.alznc.org for detailed info regarding these events.

Western Carolina Alzheimer's Association: The Alzheimer's Association will sponsor 3 Memory Walks on June 4 – Charlotte, Greensboro, Asheville. April 5, 2005 – June 15, 2005 – *Activity Based Alzheimer's Care: Building a Therapeutic Program*, 9am-4pm, Deerfield Episcopal Retirement Community, Asheville. Please contact the chapter office for more information regarding the events listed. www.alz-nc.org or info@alz-nc.org, or 800-888-6671.

**Alzheimer's 2005: Imagine the
Future
February 10, 2005**



Dr. Schmechel opens the conference with a Valentine heart metaphor.



Dr. Foster discusses the use of PET images in the future.



A four-generation family offers unique perspectives on research participation.



Barbara Thomason of Statesville, NC responds to Dr. Schmechel's comments about her role in research.



**Alzheimer's 2005: Imagine the
Future
February 10, 2005**

**Dr. Griffith answers a question for the faculty
panel on vascular risk factors.**



**A conference participant sees for himself at
the Bryan Neurobiology lab tour.**



**"Live in the Lab" with John Ervin
describing brain science.**



**Drs. Welsh-Bohmer and Schmechel take
questions from participants.**



“Genetic and Environmental Modulators of Dementia Onset and Progression”

Part One

*Donald E. Schmechel, M.D. and **Kathleen A. Welsh-Bohmer, Ph.D.

*Director, **Associate Director

Joseph and Kathleen Bryan Alzheimer’s Disease Research Center (Bryan ADRC)

Division of Neurology, Department of Medicine

Duke University Medical Center

As the current population continues to live longer, diseases associated with aging, such as Alzheimer’s disease (AD), become more common. Among those over the age of 85, approximately one-third to one-half (30-47%) suffer from some type of dementia with AD being the most common. The questions that face us as we confront this nationwide problem are: *Who develops AD and what are the underlying causes? Can the illness be treated or prevented entirely?*

In any given person, the eventual occurrence or avoidance of AD represents a complex interaction of genetic and environmental factors operating over long periods of time. Like hypertension, diabetes, and atherosclerosis, there are long periods of time where silent tissue injury occurs before clinical disease presents. This ‘silent phase’ usually ends when a person suffers a serious acute event such as a heart attack related to hypertension or gets lost while on vacation, perhaps indicating presence of AD. The actual mechanisms or cascades of events in AD begin silently. How the symptoms appear and when they become obvious are likely tied to *different overlapping causes or biological processes*. As these biological events evolve, the disease symptoms manifest and mirror the biology, progressing from normal to mild cognitive impairment (MCI), and then early-stage AD, mid-stage AD, and final-stage AD (three stages of AD).

Although some genes for AD have been identified, it must be emphasized that in the majority of persons with AD, abnormal gene ‘mutations’ do not play a role. Only about 1-2% of affected individuals carry these causal gene mutations. For the majority of affected patients, a number of variations in very common genes (“polymorphisms” or “silent” variants) interact with commonplace environmental factors, such as head injury, cardiac surgery, dietary fat and cholesterol, to influence risk, injury rate, and eventual development of AD or related dementia. Inheritance of these “risk” genes, such as the known risk gene, apolipoprotein E (APOE4), does not assure development of AD. It is the interaction of the risk gene with other factors, be these health and/or environmental factors, or the gene’s interaction with other protective or risk promoting genes that determine eventual disease outcome.

*CONCEPTS***RESERVE:**

1. The idea of “*brain reserve capacity*” or “cognitive reserve capacity” is a notion that helps explain some of the differences in the timing and appearance of AD symptoms across patients. The concept is built on the following observations of normal, dynamic nervous systems events that occur during brain development:
 - Extensive remodeling of the nervous system is a normal, healthy phenomenon, at least in early life. During the first decade of life, up to 50% of the connections and neurons in the visual system are trimmed back and removed as the nervous system develops. The young brain is used to destruction and removal of components. This cell loss, optimization and re-optimization of pathways, remodeling, and necessary debris removal are essential events for the ‘tuning’ of the nervous system.
 - Myelination or ‘coating’ of neuronal pathways is essential to nerve transmission and extends over 3 decades, tapering and stopping at age 30. The last pathways to be myelinated and ‘shaped up’ are those related to frontal cortex areas in the front of the brain related to behavior/personality.
 - Sexual maturation may affect nervous system development through effects on trophic hormones and on the deep hypothalamic-pituitary centers of the brain.
2. Extensive **reserve** exists in many neurochemical systems in the brain. For example, the pigmented brainstem nuclei of neurons of the serotonin, norepinephrine and dopamine pathways, for example, can take 85-90% ‘*slow*’ cell loss before clinical symptoms of deficiency are manifest (e.g., mood/sleep disturbance, depression, motor slowness, respectively). During aging, reserve may be lost in some systems more than others as a silent process. Vitamin E deficiency is one cause of this loss of neurons. Reserve for different classes of cholinergic neurons, important to memory, is somewhat less than in the dopamine system. Here, loss of 50-60% of neurons can result in clinical signs and symptoms (because they are ‘switching’ circuits and more closely aligned with cortical areas). This results in problems in memory and attention.
3. Significant reserves exist in subcortical brain areas that are original ‘powerhouses’ for behavior in early childhood before ‘cortical dominance’ and myelination/inhibition.
4. Unfortunately, circuits involved with memory/plasticity/adaptation in the *limbic* circuit are ***more plastic, but have less reserve***. These circuits are more susceptible to aging and injury. When one segment or section is ‘cut’, the whole serial circuit is then compromised. These circuits in the key memory structures (the hippocampus, the amygdala, and the cingulate gyrus) are among the earliest hit circuits in aging and AD.
5. APOE genotypes may affect reserve levels and neuronal shape/performance in early childhood. This effect is probably modulated by cholesterol and diet. Choline deficiency may also be critical.

RESILIENCY:

1. To understand brain ***resiliency***, it is important to know that brain reserve has dynamic capacities. The brain reserve capacity of any individual is likely created or augmented by education of all kinds, learning and practice. ‘Use it or lose it (don’t abuse it)...’ is a real phenomenon. The dynamic effects, or “learned reserves” are likely laid down throughout the lifespan but particularly early in life. They no doubt have real observable physical and

- chemical consequences in the nervous system (neurons are like plants), affecting the number of nerve branches and richness of nerve pathway redundancies (more options for processing information and adapting to injuries).
2. Age-related 'normal' injury and 'wear and tear' cannot be avoided. They can be grouped into two categories: (1) *random or one-time acute (stochastic) events*, e.g., severe illness, coronary artery bypass graft (CABG), extreme nutritional stress, head injury; (2) *chronic long-term effects*, e.g., diet, hypertension, diabetes, substance use/abuse, sleep disorders, vitamin E and C levels, exercise and learning patterns.
 3. **Resiliency** implies that the nervous system can react and heal from such injuries and achieve at least stability, and possibly total recovery.
 4. Glial cells, the supporting cells to neurons, vascular endothelial cells – brain blood vessels, and oligodendrocytes are key actors in this **resiliency** to injury. They are continually supporting neurons and their connections, and 'buffering' normal and abnormal nerve cell activity and responses. They continually remodel and fix 'wear and tear', i.e., glial cells are good gardeners.
 5. **Resiliency** is implied in the concept of **response** and **recovery** to injury and in the concept of normal aging-related changes. Homeostasis and stabilization are key endpoints.
 6. **Resiliency** implies a smooth, measured response, carefully timed and programmed in response to injury. Injury always implies glial response and 'inflammation'. **Resiliency** implies that the body's normal program of injury/inflammation response is carried out in a coordinated fashion and to successful completion.
 7. **Resiliency** depends on normal vitamin levels and anti-oxidant mechanisms which are always involved in cellular responses to injury and repair.

RECOVERY:

1. Recovery *implies an impressive stabilization and response to serious injury with presumed compromise of original reserves and initial or total failure of resilience mechanisms. Whereas resilience may play a key role in mildly abnormal aging or in persons with MCI, the degree of cell loss and injury implied even in the early stages of AD or related dementias is beyond the normal resilience mechanisms of adult brain.*
2. *If AD is caused by excessive age-related damage with loss of reserve and/or failure of normal brain mechanisms of resilience, then research into recovery is essential for the treatment of AD.*
3. *This research requires knowledge of the basic mechanisms of stem cells, normal development of the nervous system, and control of nerve cell birth and development. Most importantly, a greater understanding of the control and regulation of brain inflammatory/injury response system is needed.*
4. AD cures may involve control of peripheral mechanisms (such as amyloid beta clearance) that affect brain injury response and/or the ability to control and direct central mechanisms of inflammation and repair. Dramatic 'cures' have been demonstrated in rodent models of AD pathology, but not yet in humans.

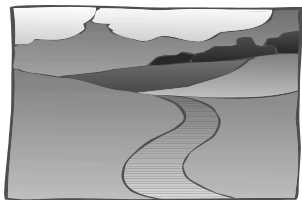
IMAGINE THE FUTURE!

Solving the scientific puzzles of reserve, resiliency and recovery will build on what we already know about vulnerability genes for AD and some of the acute "stochastic" factors (head injury, CABG,...), and continuous factors (diet, fat intake, vitamin E and C intake,...) that influence abnormal aging and AD.

We expect that there are 5-10 more genes important to AD that remain to be discovered. Clinical application will then follow.

For the person at-risk or with MCI or AD, the future is:

- analysis for relevant environmental risks and genetic vulnerability factors
- behavior modification, counseling where needed: e.g., risk of head injury, diet, substance use
- planned protection for persons at risk during/after stochastic episodes (e.g., for persons with the APOE e4 gene during/after head injury, stroke, CABG)
- identification of contributing factors such as hypertension, diabetes, vascular risk that need control, particularly for persons at highest risk
- genomic prediction of medications/treatment specific to improving resiliency and recovery
- health care including education with respect to exercise, creativity, activity to improve mood, spirit, and body/brain



Journeys

**Only those who will risk going too far
Can possibly find out how far one can go.**

T.S. Elliot



Achievements

**One never notices
What has been done;
One can only see
What remains to be done.**

- Marie Curie



Actions

**Do not be too timid and squeamish
About your actions.
All life is an experiment.**

Ralph Waldo Emerson



New Therapies for the Treatment of Alzheimer's Disease

James R. Burke, MD, Ph.D.

Several drugs have been approved for treatment of Alzheimer's disease (AD) in the past decade, but new therapies are needed. The cholinesterase inhibitors (Donepezil (Aricept); Galantamine (Reminyl), Rivastigmine (Exelon)) and Memantine (Namenda) provide modest benefit in patients, but none are proven to have a significant effect on disease progression. Many promising ideas, such as nonsteroidal drugs, prednisone, and estrogen, have been tested in patients with AD, but none has proven effective. Also disappointing was the premature termination of the amyloid vaccine trial. Amyloid plaques accumulate in the brains of patients with AD and amyloid vaccination of a transgenic mouse model of AD reduced deposits and improved cognition. Unfortunately, in some patients with AD, vaccination against amyloid led to a serious side effect - inflammation of the brain. The trial was stopped.

Fortunately, the pipeline for AD treatments remains robust and a number of clinical trials are in process or planning. GlaxoSmithKline is studying the use of Rosiglitazone in Alzheimer's disease. Rosiglitazone improves cellular responsiveness to insulin and may reduce inflammation. Impaired cerebral glucose use and inflammation are two hallmarks of AD.

Alzhemed (Neurochem) is a drug designed to stop amyloid deposits from forming in the brain. Voyager Pharmaceuticals is testing Leuprolide to determine if altering hormone signaling in the brain is beneficial in Alzheimer's disease. Still in development are drugs that block the cleavage of amyloid precursor protein, so that amyloid fragments can not form. Although progress in medicine is slow, these are exciting times and we remain hopeful that new medicines will end the scourge of Alzheimer's disease.

Do you suffer from Alzheimer's Disease or have a family member who suffers?

Duke University Medical Center is conducting a Research Study Exploring the Effects of an Investigational Drug on memory function in Alzheimer's patients.

If you would like more information about this study, please contact:

Dr. Burke at 919-684-5650

IRB # 5743





Ask a Question – Maybe Save a Life

Asking someone who suddenly becomes weak or confused to smile and repeat a phrase could save his brainpower – and his life. These simple requests are part of a 60-second test that can help determine if a person is having a stroke. Because the brain is literally being starved of oxygen minute by minute during a stroke, it's crucial to get medical help quickly.

About 700,000 Americans suffer strokes each year, but many people don't realize they're having a "brain attack" and don't get to the hospital in time for effective treatment. Most strokes (about 85 percent) are caused by an artery-blocking blood clot and administering a powerful clot-busting drug called tPA can increase the chance of full recovery by as much as 33 percent – but few patients eligible for the drug receive it, says Larry Goldstein, MD, director of Duke Medical Center's Center for Cerebrovascular Disease. The big problem: tPA must be given within three hours of the onset of symptoms, and one study has found that only 17 percent of patients get to the emergency room within this time frame. "In fact, you need to get to the hospital within two hours because it generally takes at least an hour for the evaluation process to determine if the drug can be given—but for the right patient, the sooner it's given, the better the chances it will work, says Dr. Goldstein.

Stroke is the leading cause of disability in the United States. Seventy- two percent of strokes happen to people over age 65. N.C. is in the "Stroke Belt" (States with highest prevalence of stroke).

How to Make Minutes Count

Sudden confusion, numbness or weakness of the face or limbs and trouble speaking may be warning signs of stroke. If you suspect someone is having a stroke, quickly ask her/him to:

1. Raise your arms in front of you and hold them out for a count of 10 (this spots arm weakness).
2. Smile broadly (this detects a lack of facial movement, usually on one side).
3. Say "The sky is blue" or another simple sentence (this reveals slurred speech or trouble understanding speech).

Using this three-part test, untrained adults successfully identified stroke symptoms 96 percent of the time, according to a recent study. If you give the test and the person can't respond to any of these commands – or if you're not sure what's wrong – call 911. "Minutes matter," says Dr. Goldstein. "Time lost is brain lost." Your quick action could save someone from being disabled for life.

Action
Do what you can,
with what you have,
where you are.

--Theodore Roosevelt



Humor: Easing Difficult or Painful Situations with Laughter

---Edna L. Ballard, MSW, ACSW

"Time spent laughing is time spent with the gods." - Japanese Proverb

"Children are the experts at laughter. They laugh spontaneously, at almost anything. Children under the age of 4 laugh approximately 400 times a day, compared to a middle aged adult who laughs only about 15 times per day", according to the writer in a Wellness at Duke newsletter. There are family caregivers, however, who go for days, even weeks without real laughter. Why is laughter so important? We are told laughter is good for the soul, laughter has very positive effects on us physically and laughter can relieve much of the tension we feel in our lives. Pain and fatigue may be relieved for a while. Experts suggest that pulse rate, blood pressure, circulation, the amount of oxygen and nutrients available to body tissues are all positively affected by laughter. Even the immune system which helps to fight off infection and other problems brought on by stress is strengthened by therapeutic humor. We have been admonished since biblical times that—A cheerful heart makes good medicine, but a crushed spirit dries up the bones—Proverbs 17:22. But it was not until 1979, when the New England Journal of Medicine legitimized the therapeutic use of humor by publishing the now widely known Norman Cousins case, documented first in his book, Anatomy of an Illness. Increasingly, humor has been valued by professionals and the public though there is always need for more rigorous research.

Even in periods of overwhelming anguish, families report that humor has the welcome power, at least temporarily, of distraction and respite from immediate stress. Two daughters in the Durham Evening Alzheimer's Family Support Group told others about how humor was an important coping strategy while they cared for their mother who died from Alzheimer's. To keep each other updated when their mother was in one or the other's care and especially when it had been a trying day, one daughter would call the other and begin by saying, "Well, let me tell you what YOUR mother did today....." Somehow that eased the tension or sadness of whatever catastrophe or challenging behavior had just happened. If the behavior was particularly outrageous, the reporting daughter was sure to say "Your mother did this....," which also had the effect of validating that 'this is what people with Alzheimer's do.' Telling the incident in a humorous vein helped them to deal with the painful reality of losing their mother, the person as they had known her. It does not mean there was no pain or grief there. When their father became impaired as well, the grief, anger, and other difficult feelings were just as intense, but the daughters had learned that humor can be a powerful coping tool. Humor is not a magic bullet that can be used (or is even appropriate) in every situation, but it is often a healing force that can bring relief, clarity, and even creativity in viewing and handling some situations.

Humor is not just for the family caregiver. We sometimes forget that the person with Alzheimer's also benefits from laughter. The humor may be less complicated but still provides enjoyment and a sense of social participation in something warm and wonderful, even when the person cannot remember moments later what was said or done. Cornelia Poer, a Duke Geriatric Evaluation Clinic social worker, often reminds families that even when the person with Alzheimer's can't remember what just happened, he retains the "good feeling tone" that lasts long after the event or activity. We must be mindful that at no time should the individual think he is the butt of the joke or worry that others are having fun at his expense.

Suggestions

- Early in the disease process, people with AD may use humor to cope with the diagnosis. One individual would often say "the good thing about Alzheimer's is that you can always hide your own Easter eggs," implying, of course that you can then hunt them because you've forgotten where you hid them.
- An article in the Fall 2001 issue of the American Journal of Alzheimer's Disease advises, "Laughter is one of the few things as contagious as anxiety. Moreover, laughter and smiling is something that most people, regardless of cognitive impairment, are able to do with great success. The key is not being funny, but rather seeing the humor – the irony, the absurdity, the surprise – in day-to-day situations and being able to share it."
- Families may worry that humor is demeaning in caregiving situations, i.e. "how can I laugh and have fun when this disease is so tragic?" Remember that your laughter takes nothing away from the person you care for and care about. Take off the hair shirt!
- James R. Sherman, Ph.D., in his book, Magic of Humor in Caregiving writes: "The common perception of humor is that it is fun, but it plays a much greater role than that. Humor helps you battle—with mental agility, rather than physical ability—the things that threaten you as a caregiver. It's probably the most effective way you have for getting through your (most difficult) moments." He suggests that you make it work for you by learning something new about humor and its magic every chance you get. "It can be as simple as learning the proper way to tell a joke, or as complex as learning about the therapeutic benefits of humor. Read humorists like Erma Bombeck, Art Buchwald, Mark Twain, Garrison Keillor, or any of a host of others."
- Some writers suggest when you are able to laugh at your experiences, especially in support groups, a bond forms and you feel less alone. Also, it opens up opportunities for "seeing" the situation, seeing the person with AD, and even seeing your own behavior in a new light.
- One family caregiver who had been insisting that her husband wear pajamas to bed because "that's what people do," finally saw the frantic futility of her situation. Her husband, strongly resisting, asked her, "Is this written somewhere?" The answer of course was "no." Once she was able to let go of her need to force him into pajamas, the problem evaporated for him and for her. The added benefit was her new ability to laugh at the situation.
- Sid Caesar, the comedian, said that nobody goes through life laughing all the time. When those moments of laughter happen, they are precious and they can get you through the bad times. Families are often so enmeshed in care tasks that it is difficult to find humor in the situation. Yet, the rewards for both caregiver and care receiver are worth it.

Lessons in Laughter as the Best Medicine:

"I can already hear it: 'there's nothing to laugh about when you're a caregiver.' Well, that's what I thought three years ago. I cried for a year or more—gained 20 pounds from worrying and eating—you know how that is. Cried some more and it went on and on. Then—I don't know how or when—I began to see that life does go on. And I began to realize that you don't have to wash on the same day every week, groceries will still be in the store if you don't go the same day every week, the house doesn't have to be "just so," and you don't have to eat at the same time every day—get the idea? This new attitude helped with stress and I began to see things a lot differently—little things weren't BIG anymore. And life went on.

Let me tell you a little about what goes on at my house. Wednesday night is church night. One night, I spent half an hour getting my husband ready to go to church (I always get him ready first). Then I ran into the bathroom to fix myself. Out the door we go. It had been raining, so the yard was muddy. I walked down the walk to the street. He, of course, decided to walk across the yard. Well! I looked back and there he lay in the yard, flat on his back. I looked at him and said, 'Honey, why are you lying in the yard?' (Three years ago that would not have been my response.) He looked up at me, smiled, and said, 'You know, I really don't know.' Now what can you do but laugh at that situation? He was muddy from his head to his toe. Even his drawers were muddy. We went back into the house. I stripped him, bathed him, dressed him, and we made it to church. And with a good attitude!"

---Mary W., Caregiver

Trying incidents or difficult behaviors are easier to tolerate when we adopt an attitude of tolerance for the unpredictable, the uncontrollable, the ridiculous, even the tragic. A good sense of humor takes the sting out of normally frustrating predicaments. When we decide not to become upset over the little hassles, the big ones become manageable.

From: **Lessons Learned: Shared Experiences in Coping**. (1999)
edited by Edna Ballard and Cornelia Poer

Laughter, for all its spontaneity and pleasure for most people, is very serious business. Hospitals, care centers, even corporations have recognized the benefits and have incorporated what is sometimes referred to as 'Humor Therapy.' "Since 1987, the Laugh Mobile has been a successful component of the Duke Humor Project, Duke University Medical Center. Laugh Mobile volunteers are trained for placement through the Cancer Center. The goals of a Laugh Program are:

1. To educate staff, patients, and their families on the use of humor as a coping strategy
2. To improve physical functioning and support healing through encouragement of laughter
3. To provide a catalyst for important patient-to-staff communication
4. To provide a significant tool for pain management
5. To offer a pleasant and lighthearted recreational resource which assists in the healing process and quality of life

Even in Grief and Trauma

Even in grief, humor has the ability to lessen the intensity of overwhelming loss. It becomes a benign lightning rod. Caregiving, described as "...a rocky road of fatigue, frustration, loneliness, increased responsibilities, decreased affection and companionship,"

demands a central task of simply doing the best you can in the situation. There is good advice on how to care for the person with Alzheimer's and how to cope as a caregiver. What's often missing is the discussion of humor and how useful it is to you in reducing anger and exasperation levels.

"Humor is another of the soul's weapons in the fight for self-preservation. It is well known that humor, more than anything else in the human makeup, can afford an aloofness and an ability to rise above any situation, even if only for a few seconds."

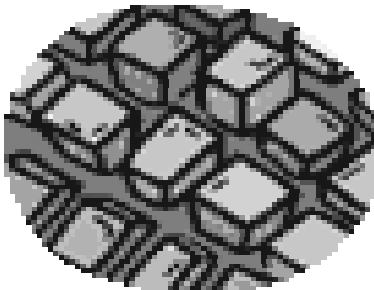
Viktor Frankl, survivor of the Nazi prison camp



Don't Wish Me happiness

Don't wish me happiness – I don't expect to be happy all the time, but it's gotten beyond that, somehow. Wish me courage and strength and a sense of humor – I will need them all.

Anne Morrow Lindbergh
(1906-2001)



Small Town

The nice part about living in a small town
When you don't know what you're doing
someone else does.

Ya Ya Sisters

Patience

When angry, count ten before you speak;
if very angry, a hundred.

- Thomas Jefferson

The Voice of Experience

Dear Edna,

You know when they say the caretaker needs to take care of themselves. Well, I didn't. I am better now. But that little statement needs to be addressed more.

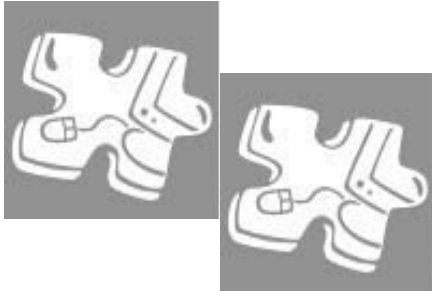
I was so stressed that I got myself into a big fat (or petite) person. I gained about 50-60 lbs. That led to having sleep apnea. That alone, if not taken care of, could cause death. I told my doctor so many times, "I am always tired." She set me up for a sleep over study. Thank God for my doctor.

But I had to quit my job because I was making mistakes. I took a leave of absence so I could keep insurance and also rest. I stayed home three months and I started doing temporary work after that. It took almost a year to get a permanent position.

I now have a sleep apnea machine. I lost 32 lbs so far. When I lose more, I probably won't have to use the machine. I am still in therapy. Taking care of my parents is an experience I would repeat, but I would have to do it differently to keep my health. I still don't know how to figure that one out. Every situation is different. There are no set rules. It was hard—damn hard. I still think about things that happen—the good and the bad. The "after they are gone" process is hard—very hard—it takes years. I am still in the process of letting go.

Take Care of Yourself, too, Ms. Ballard

A daughter requesting to be removed from The Caregiver and support group mailing list.



Losing Coherence

©Henry Walker, Durham, NC

January, 2003

Coherence,
when we know and touch all the little pieces
that hold and define us in the present
connect us with the past
anticipate the future,

Losing coherence,

a person with Alzheimer's
doesn't lose the moment
but the moment they live
can lose its ties to other moments
that we use to ground us
that we use to make sense out of our piece
which has so much of its value
in relationships,
connections,

for if we can know and feel the ties
then we can fit ourselves
into the wholes that contain us,

and not be

alone,

lost,

scared.



How Long will it Be?

How long will this go on? How many good years do we have? How will I recognize a new stage?

Families want their energies and money to last, but they do not know how to use them over time.

Know this:

- Age is the major determinant of mortality, with or without dementia.
- If symptoms progress rapidly in the beginning, they are likely to continue at that rate.
- Older people are more likely to have other chronic and sudden illnesses or injuries which may determine their “time left”.
- Alzheimer’s stages change gradually and unevenly. Assume sudden changes may be related to a new onset condition requiring treatment or requiring changes in environment or routines.

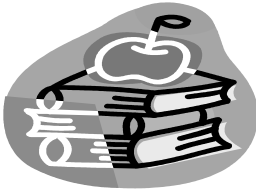
What can you do?

- Establish a routine with a primary doctor for regular visits.
- Keep a family log: review notes for changes with each other.
- Make quality time now: try health promotion, stress management skills, exercise and social time.
- Preserve your family member’s remaining skills by creating opportunities for him/her to use them often.
- Plan for handling money, care, emergency back-up and respite

Modified from Greater San Francisco Bay Area Chapter newsletter, Winter 2004.



Smooth seas do not make skillful sailors.
- African Proverb



Have You Heard About?



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CARE

The capacity to care
Is the thing which gives life
Its deepest meaning and significance.
- Pablo Casals



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www.memorybridge.org/index.html. Alzheimer's and Cultural Memory. Collective reminiscence work.

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www.accesstobenefits.org. BenefitsCheckUp provides a fast, free, confidential service to determine eligibility for all benefits for older people and their caregivers. Click on "Find Prescription Savings Now."

www.ppecc.org. Professionals with Personal Experience in Chronic Care. Chronicle personal experiences with the health care system and use them to propose policy for improving delivery of chronic illness care.

www.caregiving.org. Choose the "family care resource connection" link. Find reviews and ratings of hundreds of books, videos, websites, magazines, fact sheets and other resources addressing a range of issues and questions faced by family caregivers.

www.familycaregiving101.org. "First stop" for people who find themselves dealing with caregiving issues.

www.infoaging.org/d-stroke-home.html. New research-based stroke information.

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www.healthcompass.org. Navigating research information on aging.

www.caregiving.org. 20-page PDF Spanish-language hospital discharge-planning guide for family caregivers. Click on "Reports or Informational Products" link.

www.modelsofhopemedia.com. Find order info for dvd or vhs film "AD: A New Hope Through Understanding."

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www.caregiver.org. "Caregiver's Guide to Medications and Aging." Fact sheet that offers guidelines for safe and effective use of medications.

www.caregiving.org/alzcaregiver04.pdf. Report on why caring for a relative with dementia is more stressful than caring for one without dementia.

www.aoa.gov/press/nfc_month/nfc_month.asp. 21 consumer-oriented caregiving fact sheets.

www.kff.org/talkingaboutmedicare. Helps people on Medicare and their families make informed decisions about health care.

joann.webster@alz.org. People diagnosed with AD or related disorder before 65 years of age. The Alzheimer's Assn of OK/Arkansas is offering to help younger diagnosed people find each other. Also contact at 1-800-493-1411.

www.dasninternational.org. Dementia Advocacy and Support Network International.

www.crbestbuydrugs.org. Compare drug safety, effectiveness and cost with free consumer reports analysis.



Websites

(continued)

www.pdrhealth.com. Also, safemedication.com; intellihealth.com; and drugstore.com (prices only)

www.fullcirclecare.org. See new end-of-life resources.

www.healthinaging.org/public_education/eldercare/. This book is for caregivers on caring for someone at home.

<http://nihseniorhealth.gov/takingmedicines/toc.html>. Info about medicines and your body, taking medications safely, research and future medicines.

www.infoaging.org/l-stress-02-aging.html. Stress center tips.

www.cms.hhs.gov. Extensive information including fact sheets about the Rx benefit; Medicare Advantage, and federal regulations.

<http://www.ncbar.org/NCFindaLawyer>. NC Online lawyer referral service.

<http://www.ncmedicaljournal.com>. Alzheimer's Disease & Family Caregiving: Special Issue of NC Medical Journal: A Journal of Health Policy and Debate from the NC Institute of Medicine.

www.nihseniorhealth.gov. See new information on shingles and diabetes.

<http://www.healthyagingprograms.org>. See Falls Prevention Program.

www.storywork.com. See Richard Stone's The Healing Art of Storytelling and Stories: A Family Legacy.

www.larrywilde.com. See April Humor Month.

www.geriatric-resources.com/html/pain_assessment_in_ad.html. See PAINAD Pain Assessment in Advanced Dementia.

www.geriatric-resources.com/html/nonverbal_behavioral_pain_scal.html. (Non-verbal signs of pain in dementia).

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<http://www.careplanner.org>. End-of-life caregiver planner.

<http://www.dickinson.edu/endoflife>. Tube feeding options at the end of life.

<http://www.nclifelinks.org>. NC advance directives.

www.caringinfo.org. Free advance directive documents for any US state.

www.agingwithdignity.org. Five wishes family discussion document for end-of-life care.



Friendship

It is not so much our friends' help
that helps us
as the knowledge that
they will help us.

- Epicurus



Duke Family Support Program

Contributions

General Donations

Carole Seifer Miller
William Bullard
Harriett Walton
Shannon Crane

In Memory of Minnie Dogan

Betty Dogan

In Memory of Naomi Pepper

Barbara and Donald Matthews

In Memory of Jane Beck Pully

William R. Pully



The Eighth Annual Black Mountain Center Alzheimer's Conference
will be held on

April 22, 2005

at the

Blue Ridge Assembly in Black Mountain

Theme: PRACTICAL PATHWAYS TO CARE: LIVING WITH ALZHEIMER'S
DISEASE



If you move, please notify us by providing:

1. Your name and old mailing address
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